
CONFERENCE ABSTRACT

Improved partnerships between caregivers and care providers of persons living with dementia

1st North American Conference on Integrated Care, Toronto, 4 - 7 October 2021

Paul Holyoke¹, Justine Giosa, Heather McNeil, Doris Warner, Anna Neely

1: SE Research Centre, SE Health, Canada

Introduction

Persons living with dementia (PLWD), caregivers and care providers know the dementia journey is full of changes – in mental and physical function, care settings, care providers, and roles of caregivers and care providers in providing the “clinical” versus the more “emotional, relational” care. While “person-centred care” tools, practices and approaches are available for providers and PLWD to work together better, there are fewer tools to help caregivers and providers communicate and share their knowledge, progress and activities better so they are working better together at all times, and particular during these changes.

Aims Objectives Theory or Methods

This study evolved over time using our Participatory Research to Action framework. After a specific need was identified by PLWD and caregivers in a focus group, we held six sessions with different caregivers and providers to co-design a prototype tool to help caregivers and care providers work together better. Next, multiple co-design workshops with different communities identified prototype elements that were not relevant and how they should be changed. Each workshop was tailored in collaboration with community representatives.

Highlights or Results or Key Findings

Guided by caregivers and providers from long-term care homes and home care, a prototype tool, Our Dementia Journey Journal, was produced on paper and in an online app to respond to the identified need. We then engaged with PLWD and their caregivers in diverse communities across Canada, including First Nations communities, to see how the prototype would need to be adapted to be culturally, linguistically and geographically relevant and useful. Overall, we heard that the essential components of the prototype Journal, adapted to local needs, will be helpful to improve the care of persons living with dementia by improving caregiver-care provider relationships and shared knowledge through various changes over time. The Journal includes basic information about dementia and links to online resources, tools for encouraging exchange of questions and answers, opportunities to record changes in wellbeing of caregivers and the emotional journey of the potential Journal users surrounding a PLWD.

Conclusions

Through iterations in serial co-design sessions with caregivers and providers, we identified core elements of a tool they believe will improve their partnerships over the dementia journey with its multifaceted changes, and the necessary adaptations to make it culturally, linguistically and geographical relevant.

Implications for applicability/transferability sustainability and limitations

We have information about the different versions of Our Dementia Journey Journal to meet the needs of caregivers and providers in rural, remote, suburban, urban, francophone and First Nations communities. These various versions will now be distributed for use and evaluation of their impact on caregiver-provider relationships.